

type of surgery performed, and the ratio of elective to emergency cases.

(2) The total number of deaths occurring on the unit, both in non-operated and operated patients, together with the number of patients leaving hospital with residual malignancy.

(3) A clear separation of patient deaths in hospital into non-viable and potentially viable categories, as defined above. The non-viable group should be further subdivided into: operated cases with malignancies, non-operated cases with malignancies, and cases without malignancies. The potentially viable group should be subdivided into: postoperative deaths from a surgical complication, postoperative deaths from a medical complication, and non-operative deaths.

References

- ¹ McColl I. Observations on the quality of surgical care. In: McLachlan G, ed. *A question of quality*. Oxford: Oxford University Press, 1976.
- ² Irving M, Temple J. Surgical audit: one year's experience in a teaching hospital. *Br Med J* 1976;ii:746-7.
- ³ Salem R, Devitt P, Johnson J, Firmin R. Emergency geriatric surgical admissions. *Br Med J* 1978;ii:416-7.
- ⁴ McColl I. Medical audit in British hospital practice. *Br J Hosp Med* 1979;22:485-90.
- ⁵ Fielding LP, Stewart-Brown S, Blesovsky L. Large-bowel obstruction caused by cancer: a prospective study. *Br Med J* 1979;ii:515-7.
- ⁶ Shaw CD. Aspects of audit. The background. *Br Med J* 1980;280:1256-8.
- ⁷ Shaw CD. Aspects of audit. Audit in British hospitals. *Br Med J* 1980;280:1314-6.
- ⁸ Shaw CD. Aspects of audit. Acceptability of audit. *Br Med J* 1980;280:1443-6.
- ⁹ Shaw CD. Aspects of audit. Looking forward to audit. *Br Med J* 1980;280:1509-11.
- ¹⁰ Matheson NA, Valerio D. Large-bowel surgery, 1979, self-assessment. *Br Med J* 1980;281:719-21.
- ¹¹ Gilmore OJA, Griffiths NJ, Connolly JC, et al. Surgical audit: comparison of the work load and results of two hospitals in the same district. *Br Med J* 1980;281:1050-2.
- ¹² Gough MH, Kettlewell MGW, Marks CG, Holmes SJK, Holderness J. Audit: an annual assessment of the work and performance of a surgical firm in a regional teaching hospital. *Br Med J* 1980;281:913-8.
- ¹³ Anonymous. Audit: aiming high. *Br Med J* 1981;282:422.
- ¹⁴ Collopy BT. A surgical outcome audit. *Med J Aust* 1979;2:689-91.
- ¹⁵ Goldacre MJ, Harris RI. Mortality, morbidity, resource allocation, and planning: a consideration of disease classification. *Br Med J* 1980;281:1515-9.
- ¹⁶ Ward A. Surgical audit. *Br Med J* 1981;282:68.
- ¹⁷ Palmberg S, Hirsjarvi E. Mortality in geriatric surgery. *Gerontology* 1979;25:103-12.
- ¹⁸ Blake R, Lynn J. Emergency abdominal surgery in the aged. *Br J Surg* 1976;63:956-60.
- ¹⁹ Cogbill CL. Operation in the aged. *Arch Surg* 1967;94:202-5.
- ²⁰ Bonus RL, Dorsey JM. Major surgery in the aged patient. *Arch Surg* 1965;90:95-6.
- ²¹ Klug TJ, McPherson RC. Postoperative complications in the elderly surgical patient. *Am J Surg* 1959;97:713-7.
- ²² Griffiths JMT. Surgical policy in the over-seventies. *Geront Clin* 1972;14:282-96.
- ²³ Andersen B, Genster H, Langberg K. Geriatric surgery in a community. *Acta Chir Scand* 1965;354,suppl:1-103.

(Accepted 30 March 1982)

Contemporary Themes

Financial burden of childhood cancer

C M BODKIN, T J PIGOTT, J R MANN

Fifty-nine of 73 families of children referred for treatment of cancer during 1980 co-operated in a study of the financial consequences of the illness. Except for two social class I families who declined to take part, the sample was representative of the childhood cancer population and families were of similar socioeconomic status to the general population. During the first, inpatient, week of treatment the sum of income lost plus additional expenditure exceeded 50% of total income in over 45% of families. During a subsequent week of outpatient treatment, loss of income plus additional expenditure amounted to more than 20% of income in over half the families.

These problems affected all the groups studied and were not confined to the lower paid or those living furthest from the centre. Financial help was available from charitable sources and the DHSS towards travel, extra nourishment, and heating costs but could not be obtained

to compensate for loss of earnings. The families of children who died had difficulty in meeting the cost of funerals. Families of children with cancer need more help than is at present available, especially to offset loss of income and the cost of funerals.

Introduction

The care of children with cancer creates financial problems and hardship for their families. In an American study¹ the non-medical costs of childhood cancer plus loss of parents' pay amounted for half the families surveyed to more than 25% of their weekly income. To assess the magnitude of the problem in Britain, we studied the families of children referred during 1980 to the regional oncology centre at Birmingham Children's Hospital.

Patients and methods

A total of 98 newly diagnosed patients were referred during 1980, and on an unselected basis the families of 73 were invited to participate in the study (insufficient time was available to conduct detailed interviews with them all).

A form was designed to record family size and structure, employ-

ment status, income (including DHSS benefits but excluding Malcolm Sargent Cancer Fund for Children and similar grants), expenses incurred (travel, additional food, heating, clothing, presents), car ownership, and distance between family home and centre.

For each family the forms were completed by one of us (CMB) during interviews with the parents conducted during the first week after diagnosis while the child was an inpatient and, if possible, once more during treatment as an outpatient.

In addition the costs of an unselected sample of 10 funerals were assessed. Social class² was defined according to the fathers' occupations.

Results

Table I shows the number of families studied and their social class. Compared with the 1971 census on population² (census figures in parentheses) the social class distribution of the families asked to help was: I 2.7% (4.9%), II 13.7% (18%), III non-manual 1.4% (10.3%), III manual 43.8% (35.7%), IV 15.1% (16.2%), V 19.2% (6.6%), and not known 4.1%. Both social class I families refused to participate and four social class II families refused or failed to provide complete records, but most of the other families co-operated by providing complete financial details during the first week of their children's illness, during a period of outpatient treatment, or both.

TABLE I—Social class distribution based on fathers' occupations

	No	Social class						Unknown*
		I	II	IIINM	IIIM	IV	V	
Asked to help	73	2	10	1	32	11	14	3
Agreed and complied	59	0	6	1	25	10	14	3
Refused	7	2	2	0	2	1	0	0
Incomplete records	7	0	2	0	5	0	0	0

*Mothers did not know fathers' occupations—parents separated (2) or father dead (1).

Table II shows the diagnoses of the 59 children whose families co-operated. The proportion of patients with leukaemia was slightly greater than in the original population (27 with leukaemia and 32 with "solid" tumours, compared with 35 and 63 respectively). There were 37 boys and 22 girls aged from 5 months to 15 years (average 7.25 years). The average number of children in each family was 2.5 (range 1-6).

TABLE II—Diagnoses of children studied

Leukaemia	27
Rhabdomyosarcoma/connective tissue sarcoma	9
Neuroblastoma	7
Brain tumour	5
Lymphoma	5
Wilms's tumour	3
Nasopharyngeal carcinoma	1
Orchioblastoma	1
Histiocytosis X	1

Seven single-parent families (five mothers divorced, one separated, one widowed) represented 10.8% of the 59 studied, a similar proportion to the 12% reported for England and Wales in 1979.³ Forty-six fathers and 18 (30.5%) mothers were employed. Six (11.5%) fathers were unemployed; male unemployment rates in the West Midlands rose from 6.5% in January 1980⁴ to 13.7% in January 1981.⁵ Five fathers were self-employed. Forty-one families (69.5%) owned cars compared with 57.9% in England and Wales in 1979.⁶

Table III shows an analysis of families' finances during the first week of illness related to social class for 50 children. Weekly income ranged from £28.17 to £159.25. Some families (social classes II (3), III (10), IV (4), and V (10)) suffered no loss of income, especially (because of unemployment) those in class V, and altogether 30 of the 52 fathers were paid in full despite losing time from work. The remaining families, however, lost substantial amounts of income; loss of mothers' earnings accounted for an appreciable proportion—class II (100%), III (30.4%), IV (19%), and V (24%). None of the families was able to claim from private insurances to offset lost income.

TABLE III—Average family income and expenditure during first week of inpatient treatment related to social class

	No of families	Usual weekly income (£)	Lost income (£)	Increased expenditure (£)	Amount of income lost and increased expenditure (as % of total income)
I	0	—	—	—	—
II	6	110.51	12.50	19.77	29.2
III	22	87.68	27.02	18.66	52.1
IV	9	82.39	27.50	10.21	45.8
V*	13	66.19	6.38	10.97	26.2

*Three single-parent families whose fathers' occupations were unknown were included with the social class V families.

All families were severely affected by increased expenditure, which may have been underestimated, since some families had difficulty in recalling how much they had spent on presents and food. Unlimited visiting by relatives was permitted and free overnight accommodation for one parent per child was generally available, but nevertheless travel expenses were substantial.

The sum of lost income plus increased expenditure amounted to more than half the total weekly income for over 45% of families during the first week of the illness.

Table IV shows a similar analysis for 22 families during a week of outpatient treatment. In more than half the sum of the lost income plus increased expenditure exceeded 20% of weekly family income. The families who suffered no loss of income were: social classes II (0), III (3), IV (2), and V (5). Most families were studied during the first six months after diagnosis, so for 21 the figures included the cost of the weekly visit to the clinic. Data were not collected on the costs of treatment later on in the course, when less frequent visits to hospital are required.

TABLE IV—Average family income and expenditure during one week of outpatient treatment related to social class

	No of families	Usual weekly income (£)	Lost income (£)	Increased expenditure (£)	Amount of income lost and increased expenditure (as % of total income)
I	0	—	—	—	—
II	4	112.01	10.00	6.55	14.8
III	8	99.53	12.50	10.24	22.8
IV	4	82.87	21.87	5.10	32.5
V	6	64.07	Nil	2.46	3.8

Tables V and VI show the income and expenditure related to the distances of families' homes from the centre. As expected, the greatest expenditure was incurred by those living furthest away. During the first week of illness loss of income most affected the families living under 8 km or over 48 km from the centre. The reverse was true during outpatient treatment, probably because then the fathers were less likely to attend clinics if the journey was short or if (for long journeys) hospital transport was provided.

The average cost of 10 funerals was £246 (range £87-£434) and families received from nothing to £15 death grant, the amount depend-

TABLE V—Family income and expenditure during first week of inpatient treatment related to distance of home from centre

Miles	No of families	Usual weekly income (£)	Lost income (£)	Increased expenditure (£)	Amount of income lost and increased expenditure (as % of total income)
<5	8	79.62	24.58	6.62	39.2
5-15	14	86.93	13.30	9.43	26.1
15-30	10	79.32	2.34	14.88	21.7
≥30	18	92.22	22.78	23.90	50.6

TABLE VI—Family income and expenditure during one week of outpatient treatment related to distance of home from centre

Miles	No of families	Usual weekly Income (£)	Lost income (£)	Increased expenditure (£)	Amount of income lost and increased expenditure (as % of total income)
<5	5	70-90	Nil	1-72	2-4
5-<15	5	101-06	11-50	7-51	18-8
15-<30	8	79-61	16-61	7-57	30-4
≥30	4	114-87	10-00	9-20	16-7

ing upon the age of the child and the family's previous National Insurance contributions. The maximum death grant for an adult is £30.

CASE HISTORIES FOR FIRST WEEK OF ILLNESS

(1) The parents of a 7-year-old boy with rhabdomyosarcoma living 7 km from the centre were both self-employed and usually earned £130 a week and received £8 child benefit. Both parents stopped working when the diagnosis was made and the father claimed £32 a week sickness benefit. Travelling expenses were about £1 a day.

(2) The father of a girl aged 5 years with a brain tumour living 8 km from the centre stopped working and received £15 sickness benefit instead of his usual income of £60 (each plus £8 child benefit). Travelling expenses were £1-20 a day.

(3) The mother of a 9-year-old with lymphoma living 9 km from the centre was divorced but not receiving maintenance from her ex-husband and usually earned £65 a week. She stopped working and claimed sickness benefit of £37-50 (each plus £4 child benefit). Her journeys to the hospital cost £1 a day.

CASE HISTORIES FOR WEEK OF OUTPATIENT TREATMENT

(1) A boy aged 18 months with rhabdomyosarcoma lived 9 km from the centre. His father's income of £80 a week was not affected, but travel costs amounted to £3.

(2) The mother of a 6-year-old girl with leukaemia living 9 km from the centre was divorced and not working. Family income was £33-25 a week (£18-75 maintenance payment, £2-50 supplementary benefit, £12 child benefit). No income was lost, but the cost of travel (by taxi because the child had a procedure needing an anaesthetic) was £7, of which the DHSS paid £2.

(3) A boy aged 7 with leukaemia lived 24 km from the centre and attended hospital five days a week for radiotherapy. Neither parent went to work, so the family income fell from £92 (father's income £70, mother's £12-50, child benefit £9-50) to £44-50 (father's sickness benefit £35, child benefit £9-50). Travel cost £1-30 a day.

Discussion

The disease and its treatment impose considerable stress on the children and their families,⁷⁻¹⁰ and the incidence of mental breakdown, especially in mothers, is increased by additional stress such as marital and financial problems.¹⁰ Our findings were almost identical to those in America¹; inpatient care was about twice as costly as outpatient care, and overall the sum of lost pay plus out-of-pocket expenses represented a median of 26-2% of each family's weekly income. The problems applied to all the groups studied, and were not confined to the lower paid or those living furthest from the centre.

Apart from the non-participation of our two social class I families our sample was representative of the childhood cancer population in Britain and was similar to the general population.

The chances of curing leukaemia have been greatly enhanced by modern treatments,^{11 12} which usually necessitate an initial admission during the induction of remission lasting one to four weeks and then sometimes subsequent admissions when complications, such as opportunist infections, arise. Children living

a long way from radiotherapy centres may also need to come into hospital for two weeks for cranial irradiation. The remaining treatment on an outpatient basis lasts about three years (weekly visits during the first six months and fortnightly review thereafter). After remission has been achieved we arrange that as much treatment as possible be supervised by the family's local paediatrician. Nevertheless, nearly all the families living within 24 km of the centre and many living further away choose to continue to attend our clinic. For treatment of solid tumours similar periods of inpatient care for initial surgery, chemotherapy, and radiotherapy are necessary. The subsequent outpatient chemotherapy, however, generally lasts a shorter time (6-24 months), although occasional one-day or overnight admissions for administration of drugs may be needed.

Thus severe financial problems are being experienced by families not just during the first week of treatment but throughout the initial and any subsequent admissions. Also, the long-term nature of the outpatient treatment leads to considerable financial hardship.

Many families received financial help towards travel, extra nourishment, and heating from the Malcolm Sargent Fund for Children and other charitable sources but, although some were in receipt of supplementary, unemployment, or sickness benefits or family income supplement or a combination of these, most did not qualify for State benefits. Families could not be compensated for loss of earning by either the DHSS or charitable organisations, and help was seldom available from the DHSS or charities towards the cost of the funeral. It would be valuable if National Insurance contributions could include insurance against being unable to work due to illness in the insured's children. Such insurance should guarantee payment of the equivalent of the usual weekly wage and thus protect family income and prevent fathers having to claim sickness benefit for themselves when their children are seriously ill. An increase in the death grant to at least £100, regardless of the age of the child and previous National Insurance contributions, would also go some way towards alleviating families' distress.

Our study was confined to child sufferers from cancer, but it seems likely that equally severe financial problems may affect families of children with other severe prolonged illnesses.

We thank the Malcolm Sargent Cancer Fund for Children for financial support, the families of our patients for so generously participating in the study, and Mrs E Carr for typing the manuscript.

References

- Lansky SB, Cairns NU, Clark GM, Lowman J, Miller L, Truworth R. Childhood cancer. Non-medical costs of the illness. *Cancer* 1979;43: 403-8.
- Committee on Child Health Services. *Fit for the future*. Vol 2. Cm 6684. London: HMSO, 1976:55. (Court Report.)
- Ramprakash D, Daly M, eds. *Social trends*. No 11. London: HMSO, 1981: 3.
- Reardon S, ed. *Department of Employment gazette* 88, No 2, p 190 and No 7, p 777. London: HMSO, 1980.
- Reardon S, ed. *Department of Employment gazette* 89, No 2, p S22 and No 7 p S14. London: HMSO, 1981.
- Department of Employment. *Family expenditure survey 1979*. London: HMSO, 1980.
- Lansky SB, Cairns NU, Hassanein R, Wehr J, Lowman JT. Childhood cancer: parental discord and divorce. *Pediatrics* 1978;62:184-8.
- Lansky SB, Gendel M. Symbiotic regressive behavior patterns in childhood malignancy. *Clin Pediatr* 1978;17:133-8.
- Lansky SB, Lowman JT, Vats TS, Gyulay J. School phobia in children with malignant neoplasms. *Am J Dis Child* 1975;129:42-6.
- Maguire P, Comaroff J, Ramsell PJ, Morris Jones PH. Psychological and social problems in families of children with leukaemia. In: Morris Jones PH, ed. *Topics in paediatrics I haematology and oncology*. Bath: Pitman Medical, 1979.
- Malpas JS. Cancer in children. In: Morris Jones PH, ed. *Topics in paediatrics I haematology and oncology*. Bath: Pitman Medical, 1979.
- van Eys J, Sullivan MP, eds. *Status and curability of childhood cancers*. New York: Raven Press, 1980.

(Accepted 30 March 1982)